Underwriting Genetics in the Health and Life Insurance Industries

An Honors Thesis (HONRS 499)

by

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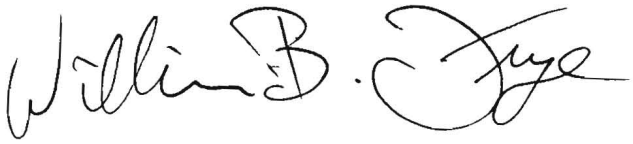

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Abstract

With the completion of the Human Genome Project, a large wealth of knowledge was gained about the basic biology of humans. The understanding of genetics has grown exponentially since then. Hidden in the DNA of every person is information about potential health risks. If this information is accurate enough, it could become an extremely valuable asset to underwriters and actuaries at life and health insurance companies. This rapid increase in knowledge of genetic diseases has also lead to fears among some considering buying insurance. Some may think that they will be treated unfairly by insurers if they take a genetic test. This paper investigates how insurance companies can use genetic information and how they currently are.

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The way that health and life insurance companies decide what an applicant should pay is called underwriting. To underwrite someone, the insurer would like to have as much information about the applicant as possible. Now, technology is rapidly advancing in nearly every area. One area in particular that may be useful for insurance companies is the field of genetics. In everyone's genes lies a great wealth of information about them. Perhaps, this information could be used to more accurately underwrite those seeking life or health insurance. However, the idea of insurance companies gaining access to our genetic information has lead to some controversy. Some people fear that they may be unfairly charged more or denied coverage. Is this the case? Are their worries legitimate? First of all, we will see need some information about what these genetic tests actually are. Also, there are some laws in place regarding this subject. Finally, we will look at insurance companies' current practices.

Genetic Tests

Genetic testing or DNA testing is a medical test that analyzes a person's genetic information. They can detect changes in genes, chromosomes, or proteins. . The results of genetic tests can be used to confirm or deny the presence of a suspected genetic disease, predict probability of developing a disease, and identify carriers of genetic disease .There are currently over 900 tests available and over 1500 diseases can be identified through these various tests.

Newborn screening is used just after birth to identify genetic disorders that can be treated early in life. Millions of babies are tested each year in the United States. All states currently test infants for phenylketonuria (a genetic disorder that

causes mental retardation if left untreated) and congenital hypothyroidism (a disorder of the thyroid gland). Most states also test for other genetic disorders.

Diagnostic testing is used to identify or rule out a specific genetic or chromosomal condition. In many cases, genetic testing is used to confirm a diagnosis when a particular condition is suspected based on physical signs and symptoms. Diagnostic testing can be performed before birth or at any time during a person's life, but is not available for all genes or all genetic conditions. The results of a diagnostic test can influence a person's choices about health care and the management of the disorder.

Carrier testing is used to identify people who carry one copy of a gene mutation that, when present in two copies, causes a genetic disorder. This type of testing is offered to individuals who have a family history of a genetic disorder and to people in certain ethnic groups with an increased risk of specific genetic conditions. If both parents are tested, the test can provide information about a couple's risk of having a child with a genetic condition.

Prenatal testing is used to detect changes in a fetus's genes or chromosomes before birth. This type of testing is offered during pregnancy if there is an increased risk that the baby will have a genetic or chromosomal disorder. In some cases, prenatal testing can lessen a couple's uncertainty or help them make decisions about a pregnancy. It cannot identify all possible inherited disorders and birth defects, however.

Preimplantation testing, also called preimplantation genetic diagnosis (PGD), is a specialized technique that can reduce the risk of having a child with a particular genetic or chromosomal disorder. It is used to detect genetic changes in embryos

that were created using assisted reproductive techniques such as in-vitro fertilization. In-vitro fertilization involves removing egg cells from a woman's ovaries and fertilizing them with sperm cells outside the body. To perform preimplantation testing, a small number of cells are taken from these embryos and tested for certain genetic changes. Only embryos without these changes are implanted in the uterus to initiate a pregnancy.

Predictive and presymptomatic types of testing are used to detect gene mutations associated with disorders that appear after birth, often later in life. These tests can be helpful to people who have a family member with a genetic disorder, but who have no features of the disorder themselves at the time of testing. Predictive testing can identify mutations that increase a person's risk of developing disorders with a genetic basis, such as certain types of cancer.

Presymptomatic testing can determine whether a person will develop a genetic disorder, before any signs or symptoms appear. The results of predictive and presymptomatic testing can provide information about a person's risk of developing a specific disorder and help with making decisions about medical care.

Forensic testing uses DNA sequences to identify an individual for legal purposes. Unlike the tests described above, forensic testing is not used to detect gene mutations associated with disease. This type of testing can identify crime or catastrophe victims, rule out or implicate a crime suspect, or establish biological relationships between people (for example, paternity).

For the purpose of insurance and underwriting, diagnostic, presymptomatic and predictive tests would be the most important. Now that we know about the

tests themselves, let's look at the laws regarding how insurance companies can use the results.

Laws on genetics and insurance.

On the federal level in the United States, a legislation known as The Genetic Information Nondiscrimination Act (GINA) of 2008, protects Americans from discrimination by health insurance companies and employers based on genetic information. Under this act, health insurers are prohibited from requesting or requiring genetic testing by the insured or their family. Also, an insurer may not restrict enrollment or raise premiums based on genetic tests. GINA does not apply to life, disability or long term care insurance. Also, GINA only applies to asymptomatic individuals.

State laws about the use of genetic information for insurance purposes vary greatly. Most laws in place today may restrict insurers from activities like using genetic information to determine eligibility or set premiums, requiring genetic testing of applicants, or disclosing genetic information without consent. As far as health insurance, almost every state has some form of anti-discrimination law in place and if they don't, GINA acts as a "floor" or minimum level of protection. Only a handful of states have laws pertaining to genetic discrimination for life, disability and long term care insurance. The table below shows which states restrict such discrimination.

State	Has law that restricts genetic discrimination for:			Actuarial justification is needed to use genetic information	Informed consent is needed to use genetic information
	Life Insurance	Disability Insurance	Long Term Care Insurance		
Alabama					
Alaska					
Arizona	X	X		X	X
Arkansas					
California	X	X	X		X
Colorado		X	X		X
Connecticut					
Delaware					
Florida	X	X			
Georgia					
Hawaii					
Idaho		X			
Illinois					
Indiana					
Iowa					
Kansas					
Kentucky					
Louisiana					
Maine	X	X	X	X	X
Maryland	X		X	X	
Massachusetts	X	X	X	X	
Michigan					
Minnesota	X	X		X	X

Mississippi					
Missouri					
Montana	X	X	X	X	
Nebraska					
Nevada					
New Hampshire					
New Jersey	X	X		X	X
New Mexico	X	X	X	X	X
New York	X	X			X
North Carolina	X				
North Dakota					
Ohio					
Oklahoma					
Oregon	X	X	X		X
Pennsylvania					
Rhode Island					
South Carolina					
South Dakota					
Tennessee					
Texas					
Utah					
Vermont	X	X	X		
Virginia					
Washington					
West Virginia					
Wisconsin					

Wyoming		X			
Total:	14	16	9	8	9

Another type of law about genetic testing that few states have adopted concerns the surreptitious collection of DNA or genetic information. This is the collection of DNA, analysis of samples or the disclosure of genetic information without the consent of the individual that was tested. A few states have laws in place that restrict surreptitious collection of DNA for health and employment related purposes as well as parentage proceedings. GINA again covers all states in this matter as well. The surreptitious collection of DNA is illegal for health insurance purposes. However, no states have these laws for life insurance purposes. That means any state in the table above with no checked boxes allows insurers to discriminate based on genetic information and it doesn't matter how they acquired it.

So we've seen that GINA prevents any discrimination for health insurance, but there are hardly any laws for life insurance. Now we just need to know if life insurance companies actually discriminate against people based on their genetic tests. To understand this, we need to know a little more about the underwriting process.

Underwriting process

Many Americans have some form of life insurance through their employers as a benefit. It is usually a small amount that is enough to pay for funeral costs but not much more. In order to cover the costs of things like college tuition and mortgage payments people need to turn to privately

underwritten life insurance. Everyone wanting life insurance must decide when to buy it and how much to buy. They also need to decide which type of insurance to purchase. The products range from relatively cheap term insurance to high cash value single premium whole life with many different types in between. When choosing which type to buy, people must consider their current income, coverage needs and if they want a cash value policy or a term policy and invest the difference. There are more than 1,200 insurance companies in the U.S. competing to meet the specific needs of all consumers.

The only thing common to all forms of life insurance is the transfer of financial loss from the insured to the insurer in the event of a premature death. To offer this, the insurance companies need to be able to determine the risk associated with each applicant and invest wisely so that they will have enough money to pay future claims. Different groups of people pay different prices depending on the life expectancy or risk of death associated with them. Life expectancy depends on age, gender, life style, occupation and health conditions.

The purpose of underwriting, or risk selection, is to decide into which group to place an applicant. Most people with no history of disease or major risk factor are placed in a large group considered to have standard mortality. The premium assigned to a group is determined by the expected rate of death. People with different diseases may be placed in the same group if they have the same life expectancy. For example, someone with diabetes and a person with coronary artery disease have double the expected annual mortality so they would both pay the same amount.

The job of underwriters is to determine life expectancy based on medical, occupational and other factors that might affect life expectancy. It is important that the insurance company has knowledge of the applicant's situation in order to accurately evaluate the risk of mortality. With so many companies competing to sell life insurance, underwriters must be accurate to place an attractive price on the policy.

All insurance companies have different business models, investment philosophies, and target markets. Some sell mostly term insurance to younger crowds. Others sell mostly high cash value insurance to more affluent people. Some companies only want to insure those with low mortality rates while others aren't so picky. This competitive market allows consumers to have many options when buying insurance even if they have a disease or some other risk factor. Companies have medical staff and underwriting specialists that stay informed on the impact new medical knowledge, disease treatments and tests have on mortality. When an applicant has a certain known disease, it is up to the medical underwriter to assess the risk and its impact on mortality. The free market aspect of the insurance industry ensures that all customers can get the best price, regardless of their medical condition.

People in large groups will die at a predictable rate. This holds true whether the group is composed of healthy individuals or if everyone in the group has the same disease. Life insurance companies use mortality tables (also called life tables) for each risk category. A mortality table shows the number of deaths expected in each year of life for a group of people. Below is a shortened mortality table to serve as an example. Almost all mortality tables will show

mortality rates until the age of 100 with some going to 120. This particular table shows the mortality risk for the entire United States population only until age 45. Other tables will be more specific in regards to gender, race, smoking habits and health risks.

Life table for total population: United States, 2003

Age x	Probability of dying between ages x and x+1	Number alive at age x	Number dying between ages x and x+1	Expectation of life at age x
0	0.006865	100,000	687	77.5
1	0.000465	99,313	46	77
2	0.000331	99,267	33	76.1
3	0.000259	99,234	26	75.1
4	0.000198	99,208	20	74.1
5	0.000168	99,189	17	73.1
6	0.000151	99,172	15	72.1
7	0.000142	99,157	14	71.1
8	0.000139	99,143	14	70.2
9	0.000134	99,129	13	69.2
10	0.000165	99,116	16	68.2
11	0.000147	99,099	15	67.2
12	0.000176	99,085	17	66.2
13	0.000211	99,067	21	65.2
14	0.000257	99,047	25	64.2
15	0.000339	99,021	34	63.2
16	0.000534	98,988	53	62.3
17	0.00066	98,935	65	61.3
18	0.000863	98,869	85	60.3
19	0.000925	98,784	91	59.4
20	0.000956	98,693	94	58.4
21	0.000965	98,598	95	57.5
22	0.000987	98,503	97	56.5
23	0.000953	98,406	94	55.6
24	0.000955	98,312	94	54.7

25	0.00092	98,218	90	53.7
26	0.000962	98,128	94	52.8
27	0.000949	98,034	93	51.8
28	0.000963	97,941	94	50.9
29	0.000998	97,846	98	49.9
30	0.001014	97,749	99	48.9
31	0.001046	97,649	102	48
32	0.00111	97,547	108	47
33	0.001156	97,439	113	46.1
34	0.001227	97,326	119	45.2
35	0.001357	97,207	132	43.3
36	0.00146	97,075	142	42.3
37	0.001575	96,933	153	41.4
38	0.001672	96,781	162	40.5
39	0.001847	96,619	178	39.5
40	0.002026	96,440	195	38.6
41	0.002215	96,245	213	37.7
42	0.002412	96,032	232	36.8
43	0.00255	95,800	244	35.9
44	0.002847	95,556	272	35
45	0.003011	95,284	287	34.1

Source: National Vital Statistics Report, Vol. 54, No. 14, April 19, 2006

An underwriter must be able to interpret medical advances differently than traditional medicine. For example, suppose a new medicine was introduced that treated a certain disease and claimed that among 40 year old patients, 99.5% survived the first year of treatment. This may seem like a large portion of the patients are survivors, but when the numbers are examined more closely, the results aren't so great. A 99.5% survivability means that out of 1000 patients, 5 will die within a year. From the chart above, the standard population would only experience 2.026 deaths per 1000 people. While a 99.5% chance of

surviving some disease may sound good, the risk of death is actually 2.5 times higher than a person with no disease.

Another example of why mortality tables are so important in figuring the price an applicant should pay deals with tobacco use. While intuition may say that someone who smokes will only have an increased risk of mortality at higher ages, the truth is different. In fact, smoking and most diseases increase the death rate in a consistent fashion for each interval of life. The table below shows the expected deaths of smoking and non-smoking men.

Number of expected deaths per 1,000 men per year for smokers and non-smokers

Age	Non-Smoker	Smoker
30	0.32	0.68
50	1.08	2.16
70	5.94	11.98

Source: *Medical Underwriting*, Robert K. Gleeson, MIT Press

The table shows that for any age, a non-smoker is half as likely to die before his next birthday as a smoker. This is counterintuitive to those who think a smoker's risk of mortality only increases at higher ages. Also, the very low mortality rates should be noted. A genetic disease that leads to only one death in a thousand may seem low, but to a person age 30, it would double his or her likelihood of death.

Most differences in mortality for a given age, gender and smoking status are related to health factors. These factors could be occupational, avocational or habits like driving records. Insurers are interested in knowing as much information about the applicant's health as possible to insure accurate

underwriting. Almost all applicants are asked questions about their current health, any major illnesses or surgery in the past and their family history of diseases. For larger amounts of insurance, saliva or blood tests may be implemented to test for HIV, nicotine or recreational drugs. At even higher amounts, blood tests may be used in order to test for disorders of lipids, glucose and liver or kidney functions. At still higher levels, insurers may require an electrocardiogram, chest radiograph or a statement from the applicant's physician.

Mortality Rates and Genetic Risks

With the completion of the Human Genome Project, a great deal has been learned about basic human biology. We have learned about hundred of genetic mutations and which diseases they may cause. Along with this knowledge came the fears of some who think it may be used against them. One area where people feared this newfound information may be used maliciously is the life insurance industry. But is there anything to worry about? Will more accurate genetic tests lead to higher insurance prices?

Many of the concerns people have are that if they take a genetic test, they might pay more or be denied for life insurance. These concerns are based on a misunderstanding of the underwriting process. As explained earlier, underwriters use medical and actuarial information to determine life expectancy and an appropriate premium. Genetic tests give more information to the underwriter so the calculations can be more accurate. Currently, most genetic mutations that could potentially lead to diseases have little or no actuarial information attached to them. The probability of developing a disease is still unknown for many mutations.

Life expectancy for a group of people is defined as the number of years that one is expected to live as determined by statistics. A person's life expectancy is always changing as their age changes. As age increases so does life expectancy as long as there is no change in health. To determine an individual's life expectancy, an underwriter would examine their medical history, family history, laboratory tests, and lifestyle. Applicants who have an increased risk of a medical incident, such as a heart attack, but have not actually experienced one will have a lower life expectancy than someone without an increased risk.

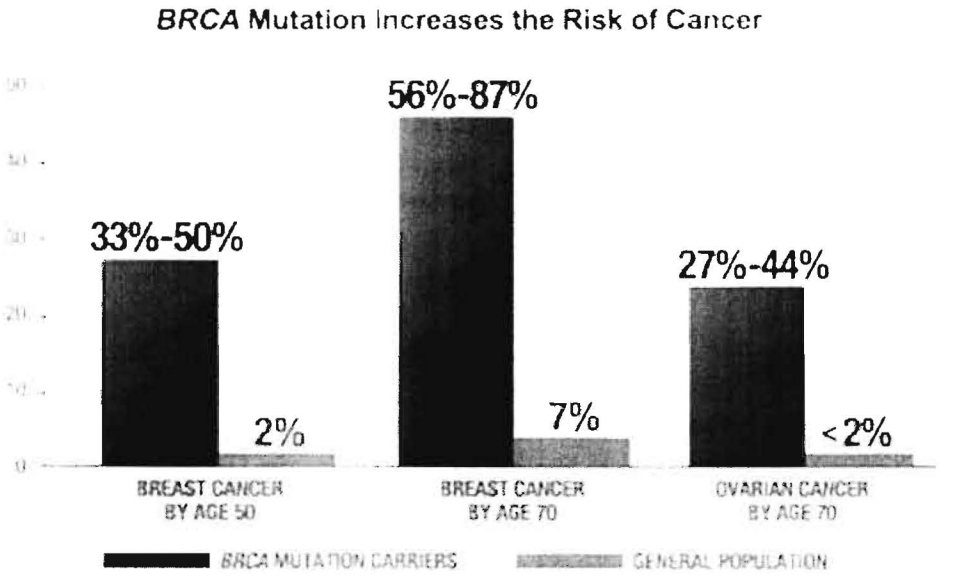
There are many different types of tests to help determine mortality rates. Very simple tests like determining obesity and high blood pressure indicate a higher mortality rate, and therefore a lower life expectancy. More complicated laboratory tests can check for hepatitis or diabetes. An individual could seem perfectly healthy before these diseases begin to show symptoms. Even though the person might be ostensibly healthy, his life expectancy would be lower than if he really was healthy. Genetic testing is different because it shows increased risks that may not be showing symptoms and may not be identified by simple medical tests or family history.

Our knowledge of which mutations are linked to disease has increased very rapidly in the past few years. There are tens of thousands of known mutations. Clearly all cannot be listed here. To research further a database of most known mutations can be looked up on websites like http://www.ncbi.nlm.nih.gov/ (the national center for biotechnology information) and http://www.hgmd.cf.ac.uk/ac/index.php (the Human Gene Mutation Database at the Institute of Medical Genetics in Cardiff). However, there are only a few diseases for which we know the certainty of a disease becoming present. A few prevalent

for which we know the certainty of a disease becoming present. A few prevalent genetic diseases have been studied for years and the probability of developing the disease based on the genetic mutations can be determined. The morbidity and mortality rates of some of these mutations will be discussed below.

Breast and Ovarian Cancer

Mutations in the BRCA1 and BRCA2 genes are known to cause an increase in the risk of developing breast and ovarian cancer. Together these mutations cause 10% of all breast cancer. The following chart shows the risk of developing breast cancer after a genetic test is positive for a BRCA mutation.



Source: www.brcanow.com

Many women might think that a positive result is a bad thing. Relative to a negative test, it is not a good thing, but with an early enough detection of the mutation, preventative measures could lower the risks of developing cancer. A woman seeking life insurance with a family history of breast cancer may fear that if

she takes a BRCA test and it is positive she will have to pay a higher premium. This is not the case, however. By showing that she is working with her physician to make a management plan, she can lower her risks down to the same level as the general population. The next table shows the survivability depending on which stage of breast cancer a woman has. The numbers come from the National Cancer Data Base, and are based on women who were diagnosed with breast cancer in 2001 and 2002

Stage of Breast Cancer	Five Year Survivability
0	93%
I	88%
IIA	81%
IIB	74%
IIIA	67%
IIIB	41%
IIIC	49%
IV	15%

Source: www.cancer.org

Women who know they carry a BRCA mutation can be alert and take preventative measures. Those who do not take the genetic test may be in stage II or III before they are diagnosed. Any woman with a family history of breast cancer should be encouraged to take the genetic test. If it is negative, their insurance rates may be lower than if they chose not to.

Huntington Disease

Huntington disease is a neurodegenerative genetic disorder that affects cognitive ability and leads to dementia. It is incurable and usually becomes symptomatic around the age of 30. The life expectancy of an individual with

Huntington disease is about 20 years after the symptoms are present. It is an autosomal dominant disorder with 100% penetrance. An affected parent has a 50% chance of passing on HD to his or her child.

Consider a 25 year old man whose father died of HD at age 50. He doesn't want to get a genetic test but does want life insurance. He has a 50% chance that he will not live to be 50 years old. In this case insurers would add a small, flat, extra amount to the premium for at least the first 15 years of coverage. This would cover the increased risk. If the symptoms of HD never showed up, the extra amount could be dropped. In both the case of breast cancer and Huntington disease, underwriters are able to place the applicant into the correct group and give them a fair price. We have seen in theory that underwriters could use genetic tests, but do they?

How are genetics currently used in the insurance industry?

While, like it has been said before, genetic testing has been advancing rapidly, there are still very few insurance companies utilizing them. In fact, no companies require them for health or life insurance. Some argue that our understanding of genetics is moving and changing too rapidly for statistical support to be established. Another reason that genetic tests are rarely used is the cost. The average total cost for general laboratory testing, including collection, is around $100. Genetic tests are much more depending on the type. The chart below shows the prices of several different tests available.

Cost of Genetic Tests by Disorder and Type of Test					
Lab Test	**Sequencing**	**Heteroduplex Analysis**	**DGGE**	**ASO**	**PTT**
HNPCC	$500-$3000	$260	$250-$800	---	---
FAP	$800-$1000	---	---	---	$235
BRCA1	$1,290	---	---	$350-$450	---
BRCA2	$1,290	---	---	$350-$450	---
Huntington	$600-$1500	---	----	---	---

DGGE- Denaturing gradient gel electrophoresis
ASO- Allele specific oligonucleotide
PTT- Protein truncation test
HNPCC- Hereditary nonpolyposis colorectal cancer
FAP- fibroblast activation protein

Increasing the cost of testing the applicant by even $100 more would result in raised premiums. So unless the applicant is seeking a very large policy, there is currently no justifiable reason to order such expensive tests. In the future, however, it is likely that the accuracy of the tests will improve, the costs will decrease and statistical information will exist on the subject. Until then, the tests will rarely be used by insurance companies.

Underwriting works most efficiently when the applicant and insurer have the same knowledge about the applicant's medical situation. An applicant should not withhold information in order to pay less for insurance. Nor should someone forgo a genetic test out of fear that the insurance company will discriminate against them. If an underwriter overcharges, the company will lose business to competitors. With so much competition among companies, an applicant cannot be unfairly charged no matter what their condition. With

genetic tests advancing in their accuracy, they will be implemented more in the insurance industry and lead toward better underwriting.

The field of genetics is rapidly growing and changing every day. Many people are not able to stay informed on all the new advancements. They are unsure of the proper course of action when it comes to getting a genetic test for insurance purposes. They may be afraid they will face negative consequences if they take the test. This should not be the case, however. If someone considers genetic testing for any reason they should not reconsider because they think their insurance will cost more. Having this information can help prevent an individual from becoming ill or even save their life.

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